2001

Ethical Aspects of Prenatal Genetic Diagnostics

Hille Haker
Loyola University Chicago, hhaker@luc.edu

Ethical aspects of prenatal genetic diagnostics

Hille Haker

Center for Ethics in the Sciences and Humanities - University of Tübingen

Introduction

In this essay I will consider genetic diagnostics, especially pre-natal diagnostics, with a brief reference to pre-implantation genetic techniques. I will focus on a moral discussion of the subject and will try to clarify a number of aspects. However I will not give a definitive and indisputable answer to the normative questions which have been raised by new technical possibilities. To this regard everyone should consider themselves invited to an open debate, a debate that has as yet been on the whole conducted badly and that cannot be brought to a hasty conclusion by drawing on outdated beliefs.

Self-fulfilment ethics and normative ethics

In the past years the difference in terminology between the two fundamental aspects of ethics has been framed in many different perspectives. When we distinguish between everyday ethics on one hand and theoretical reflection on ethics on the other, we can use the concepts of "values" and "norms" for the former, and the concepts of "ethics of self-fulfilment" and of "normative ethics" for the latter. Unfortunately, in the German-speaking world authors have not yet reached a clear consensus on terminology: some intend "ethics of self-fulfilment" also as "ethics of well-being" or as "eudaimonistic ethics", whereas others refer to "normative ethics" also as "ethics of moral obligation" or as "moral theory" in a strict sense.

But what do these concepts mean exactly? They refer to two very different perspectives of the contemporary ethical search, which have two different points of departure and two different directions: *ethics of self-fulfilment* is above all concerned with the idea of a successful life, and is particularly interested in indicating the concepts of life and values on which this idea is grounded. This type of ethics also raises issues involving individual and social experience, history, memory, medical diagnostics and future-prospects, with particular reference to social and individual recognition. Ethics of self-fulfilment questions whether the moral convictions on which our practical behaviour is grounded are plausible, consistent and compatible with our real possibilities. Particular values could be (at this

level of everyday ethics) useful in situations of conflict as they might provide our conduct with continuity: and, of course, continuity is essential to us. Although this conduct might be readily shared by many individuals or groups and therefore develop a specific normative force, ethics of self-fulfilment (intended as a theory of practical values and successful life) avoids judging whether these convictions and the ensuing behaviour are absolutely valid for everyone. That is, ethics of self-fulfilment analyses the beliefs of the agents, questions the traditional values, advises those who need advice (with reference to plausibility and consistency) in situations where a decision has to be taken, indicates possibilities which had been neglected or ignored by the agent. Its task is, to a certain extent, hermeneutic, i. e. ethics of self-fulfilment throws light on the aims and opportunities of the agent and at the same time guarantees him continuity. This kind of ethics does not have a prescriptive value, i. e. it is descriptive and indicative rather than normative (or at least, it has a limited normative force). For this reason ethics of self-fulfilment is not grounded, as on the contrary normative ethics is, on the categorical validity of moral judgements and rights: this type of ethics produces, in Kantian terms, *hypothetical* judgements whose normative character is naturally limited; the different options of actions are subordinated to the aims and ends which the agent considers essential. The ensuing duties are called, again as in Kant's tradition, *imperfect duties:* they do not have a universal validity and therefore they are connected to the perfection of the action chosen to fulfil them.

Normative ethics goes in a different direction. This ethics does not investigate the personal ideas and aims of the agent: it presupposes them. As ethics of self-fulfilment focuses on the agent's interests and rights, normative ethics brings into play the interests and rights of others. If we hold that consideration of others is central to morality, this ethics can be regarded as "morality" in its higher sense. Its task is therefore to question the justification of actions and the grounds of the rights that are -or could be- assigned to agents: only the so called "legitimate" (i. e. justified) interests of others require a corresponding obligation. A stronger formulation of this concept can be traced in the theories of moral rights, whose duty is precisely that of making explicit and especially of giving the grounds for the fundamental rights (i. e. the rights which all humanbeings share).

The duties outlined by normative ethics require a categorical validity and expect from all agents the respect of the rights of others, of those rights whose justification has been demonstrated. The main difficulty consists in the fact that this ethics must consider the rights of different individuals (not only those of one single agent) and therefore its task is also to find a satisfactory balance between these different interests. For this reason a

theory of justice is an essential constitutive part of normative ethics.

The two fundamental perspectives of ethics therefore hinge on choosing between an individual or a social direction. Not only is the coordination and ranking of ethics of self-fulfilment and normative ethics an open question with many different answers; even the evaluation of individual and social ethics can lead to a situation of conflict. The following framework, while providing us with a formal pattern for the two different fields, also demonstrates that they cannot be described one without the other.

Framework

This formal outline provides us with the object of ethics. In particular the different theories are compared point by point: this might, as I have already said, lead to problems of coordination. However, the four above mentioned dimensions give us the opportunity to propose a definition of ethics:

Ethics is the theory of man's self-fulfilment and duty. It questions the individual concept of life and social values: both are aspects of the individual/social aspiration to a successful life. Moreover, ethics throws light on the issue of rights: rights which are claimed by some and must be respected by others. Ethics also tries to find a way of balancing the interests and rights of different individuals and different groups. In this sense ethics calls upon those institutions and power-structures which are connected to the problem of rights.

2. Analysis of the problem of pre-natal diagnostics

-Questions of self-fulfilment ethics-

Individual ethics/Social ethics

Individual concepts of life/ social values "Decision making before/ after the discovery of an illness/ after the diagnosis: values, convictions, ideals (differences with the partner's set of values).

Possibilities of integration in the personal history "Attitude towards abortion" "Attitude towards risks"

Quality of life and well—being: "Cultural concepts: pregnancy, birth"

Concepts of human life "Shared social values (self—determination, autonomy, family, quality of life, health…)"

Social attitude towards handicapped people and handicaps in general (normality vs. defect).

- Normative—ethical questions -

Justification of rights : "Rights of those involved (woman vs. baby?)" "right to self-determination"

Abortion "The status of the fetus"

Responsibility of doctors and advisers; criteria of advice (non directivity) "Individual eugenics? (Selection)": "Selection through lists of illnesses and screening?" "Criteria for advice and for medical conduct"

Some aspects of social justice: sharing of costs in the health service (costs of pre-natal diagnostics in proportion to total cost) "Benefit payments"

"right to integration, to education and to work?" Legitimation of commercial interests: "Socially legitimated eugenics"

International aspects of pre-natal diagnostics.

All these aspects outline problems which in the individual case are very hard to solve. However this brief framework might be of some help in illustrating, even if only temporarily, public opinion. This listing of problems opens a wide range of opportunities for individual evaluation and for practical conduct with reference to the issues of pre-natal diagnostics. This listing shows that the perspective of those involved is completely different both from that of professional advisers and of doctors and from that of society itself, as far as this personal perspective is accessible through media, literature on abortion and personal experience.

The task of ethical theory is to coordinate the different aspects and, if possible, to rank them, therefore making possible a moral evaluation possible.

3. Ethical evaluation

3.1 Towards the concept of responsibility in ethics

In the next part of my fragmentary ethical analysis I would like to clarify my personal approach. My point of departure will be the concept of responsibility. In my opinion this concept enables mediation between the two different levels (ethics of self-fulfilment/ normative ethics). It must be made clear that responsibility does not only regard others (or the rights of others) but also refers to ourselves, to our personal history, to our values, assets, aims…

Aside from the normative dimension, responsibility can be defined as a (moral) attitude of care for oneself and for others, an attitude which might

well be indicated as basic moral conduct.

In no way does responsibility only refer to present choices and situations: its horizon is located in the past and in the future. If we intend responsibility in such a way, the historical dimension of agents is easier to understand: it is this very dimension which is able to create both norms and continuity in conduct. When I use the concept of responsibility as the possible mediation between the different ethical levels, I am asking myself (with reference to concrete situations) *which agents (and institutions can be considered as agents) are responsible, towards whom and in what way.* Although I will not avoid facing later the problem of responsibility in relation to duties (duties connected to the rights of others), I will however continue to use my own perspective in order to indicate the moral subjects who play an important role in the problem of pre-natal diagnostics.

Notwithstanding the request to extend the debate to include a reflection on values both as regards the individual and socially, the moral-normative relationship towards the fetus is central to the discussion of pre-natal diagnostics. However my opinion is that, far too often, in ethical analysis two serious mistakes are made: firstly the highly moral request for protection is limited to the holders of moral rights; these are people who not only have interests but who are also capable of fulfilling their duties; what is therefore highlighted is the symmetrical relationship between individuals: the different requests of rights are handled and discussed with reference to this relation-ship. It is no wonder that the model for this type of relation is always the theory of social contract. At this point, however, a question naturally comes to mind: why should the prohibition to kill (intended as the negative right not to be killed) be valid also towards children who definitely are not moral subjects in the sense of "responsible agents"? What I mean is that the idea that the prohibition to kill is valid for indirect reasons (piety or reasons concerning the brutalisation of others) does not work as a description of concrete situations. The prohibition to kill, referred to children, clearly shows us that categorical duties exist also in non-symmetrical relation-ships: these duties directly stem from the need for protection, they do not stem indirectly from the status of the other individual, from his being a bearer of rights. In non-symmetrical relationships duties and rights do not converge.

The second mistake is to make use of a reductive concept of personhood as a basis of the ethical analysis, a concept in which the anthropological link of body and soul is lost: in Gewirth and Steigleder for example the capacity of action and of moral thinking is the basis for the allocation of rights. This terminology, however, is not clear and precise. The origin of the capacity of action, for example, is not thoroughly considered. The whole question of "passive rights" or, in more moderate terms, of "passive

protection" remains unanswered: and this is something which cannot be ignored nor underestimated. In Gewirth's and Steigleder's theory of human personality the central point for the acknowledgement of rights is exclusively the capacity to develop autonomously personal aims. But aren't other aspects of personality —for example the corporal and temporal contexts, the need for social recognition for the development of personality- also of normative relevance? And couldn't these aspects overcome the weak points of a unilateral vision of personality and therefore enable an understanding of the fundamental (or imperfect) duties? In this sense the concept of personhood is important both to determine the agent's rights — and with reference to the pre-natal diagnostics of the embryo's rights- and to clarify of the so called subject of responsibility. The rights' issue is part of the wider context of the responsibility which a person has towards another person. Responsibility is not, for the supporters of a "moral theory" in its strictest sense, exclusively related to people, but also to animals, the environment and so on.

The analyses of rights must however supply us with some practical criteria useful in the search for a balance in those situations of conflict where two or more rights are to be considered. In principle (i. e. apart from the ever tragic situation of conflict) human beings have a generic responsibility to protect of embryos and fetuses, whatever individual characteristics they might have. In the field of pre-natal diagnostics there definitely is what we have called a conflict of rights. Can the change of perspective I have so far adopted to explain the concept of responsibility be of some help? In my opinion it can.

3.2 Responsible parents and pre-natal diagnostics

The social changes which have affected the concept of parenthood do not leave the idea of responsibility undisturbed: it must be made clear whether donors of sperm and eggs are responsible for their children as "genetic parents" or if, once they have given their contribution, they leave the scene. Moreover, it must be made clear whether the State or other institutions should request, before marriage, genetic tests in order to show the pre-disposal for certain illnesses.

This is not the place to develop a wide vision of responsible parenthood under the circumstances of pre-natal diagnostics. It must be however considered that most of the invasive diagnostic techniques are carried out for reasons of age. These pregnancies are usually planned and strongly desired. The moral conflict is provoked however by the diagnostic discovery of a health problem in the child. By "pre-natal" diagnostics we intend the chromosomic and genetic analysis of the hereditary

characteristics of the baby, analysis which still has to be clinically discussed, for it does not allow a precise prognosis of the illness. There is clearly, for the rest of the pregnancy, an evident psychological (more than physical) burden for the woman, a burden related both to the incomplete information given by the diagnosis and to the shattering of the ideal vision of the baby. Essentially what is damaged is an expected condition which will take place only after the birth, and this however must not be underestimated. The question is whether women, couples or parents have an adequate comprehension of parenthood when they know, before the pregnancy, that they will terminate it should a pre-natal diagnosis discover an illness. This can be considered as the first case of responsibility. Before the introduction of pre-natal diagnostics couples had to ask themselves whether they would eventually have been prepared to take care of a handicapped or sick child, and in many cases those couples with a hereditary problem or in an advanced age decided not to have children. Pre-natal diagnostics has shifted the problem in the direction of the tests and of abortion in these circumstances. Nowadays we must ask ourselves whether parents can make a request for quality — and health certainly is such a request — into a condition for the acceptance of their child. My opinion is that parents owe this to their children, especially if we think of the importance of social recognition: the idea of a generic responsibility towards human life is not entwined with an adequate concept of parenthood.

In many cases we do not have the possibility to chose whether or not we want to take responsibility: we are responsible, without having asked for it, for example towards our family and our loved ones. With conscious procreation couples enter the circle of parents as free agents: they are responsible for their children until they become autonomous. However, even in the best social and ethical conditions we will have situations in which women or couples, who initially wanted to have children, eventually decide they can not take that responsibility. The juridical formulation of this situation is somehow implicitly given in German Law (218a). Moral judgement must however wait for the final decision of the woman, she alone can decide what limits her capacity for responsibility has. In ethical terms, prescription of duty presupposes practical capacity. In the absence of conditions for taking responsibility, the requirement of duty, although valid in itself, is not practically feasible. Hence it is necessary, when advising an expectant mother, to explain the problem of responsibility before the pre-natal diagnosis: a specific+ training of the advisers is therefore needed. Not only the juridical formulation but also the ethical opinion leaves open a grey area of action, which must be classified as a particular case of individual choice.

3.3 Responsibility of the doctor in pre-natal diagnostics

The relationship doctor-patient can be considered in two ways. Doctors and clinical staff are not only responsible for assisting the pregnant woman as a patient; they also have to assist the embryo or the fetus. The fetus is certainly protected by the mother from any external intervention; however the relationship of the woman towards the doctor is fragile, especially if it is a question of the baby’s health; moreover the technical developments of the last decade have increased the doctor's possibility of action and accordingly a reconsideration of the doctor's responsibility is necessary. His responsibility does not only lie in the decision to practise an abortion. It also lies in choosing to accept the risk of a miscarriage due to the use of invasive diagnostic techniques. Up to now this field has been regarded as an ethical taboo. For this very reason the role and importance of advice before diagnosis is often neglected: the future mother finds herself in a situation which she has never really thought about and has to take a decision without having enough professional advice.

The relationship doctor-patient is always understood to follow the model of gynaecology and assistance to expectant mothers. Let's consider however the context of medically advised abortion: its model has its limits and indeed overlaps with that of neonatology and pediatrics. In this latter model the parents' autonomy is strongly limited by the baby's right to protection. In situations of conflict doctors very often decide against the parents' interest, as far as the baby's life and well-being are concerned. There is a subtle transition from the model of gynaecology to that of pediatrics. At the beginning of the pregnancy the assistance to the mother is in the foreground, in accordance with her autonomy. Towards the end, however, the fetus gains more and more importance. My opinion is that at this point professional self reflection is needed, in order to identify the doctor's specific responsibility, with reference to the pregnant woman, with reference to the relationship towards a terminally ill fetus, whose illness can be traced before birth, with reference to the pre-natal killing of fetuses who would live, with reference to the relationship towards living infants after an abortion.

Moreover, it will be a specific task of the professional orders to organize training courses so as to give doctors, social assistants and obstetricians the capacity to handle a situation of conflict in the best way. In these courses a fundamental role should be played by the psychological (treatment of psychological traumas), social (unlimited recognition of handicapped/sick individuals as a required value for a supportive society) and ethical aspects.

3.4 Social responsibility in pre-natal diagnostics

I can not thoroughly explain in this paper the social and ethical

consequences of a policy of social recognition of man’s early life; I will not however dissimulate that I firmly criticise the trend of the past years, that has lead —in the field of pre-natal diagnostics- to a praxis of "bottom-up eugenics" , that is to an individualistic and voluntary eugenic behaviour, grounded however on a form of "voluntary constraint". When exception becomes the rule the social sense of responsibility fades. Significant changes of values should always be followed, step by step, by an ethics of self-fulfilment. When solidarity seems at risk, it is duty of the different institutions involved to ensure social recognition. This is not only valid for the public health service, for the medical and non-medical insurances and for the whole health system, but it is also valid for the instruction system and for mass-medias, which in particular lead the transmission of values. The moral culture of a society, and not exclusively its "contingent" national Law, has the specific task of welcoming its members and of providing them with an adequate social place. The occidental societies as yet have not developed such a conduct, and very often too much is asked of us as single individuals. Gynaecological associations, clinics, rehabilitation centres, medical insurances, nursery schools, schools and even companies are institutions and must recognise —in different ways- handicapped children and adults. *One* possible form of recognition consists in the stabile organization of advice and support groups for the therapeutic assistance of woman and couples. Doctors themselves must respect the responsibility deriving from the changed relationship towards both their patients. With the increase of genetic tests this issue is extremely urgent.

Our society will have to prove —in the years to come- whether the shared values which have grounded our attitude towards handicapped people from the second world war on will be valid also for the next century. Faced with the new medical developments and with the continuous erosion of society such a reflection is essential.

The relationship towards children mirrors the vision a society has of the relationship towards those who need assistance. Medically assisted procreation belongs to this context: when the limited acceptance of a child —which in normative sense I interpret as limited respect- is decided from the moment of the procreation or at the very beginning of the pregnancy then not only is the baby’s protection weakened: also the acceptance of "deviation" from the so called "normality" is at risk. The acknowledgement that normality in itself is plural and therefore allows difference and diversity will not be easy to achieve. In ethical terms this shows on one hand the extreme fragile nature of the concept of recognition in our society, and on the other it demonstrates that the recognition of the "special" and particular nature of each of us is a constitutive part of the idea of man’s continuous development and therefore is the other side of normative equality.